

ARIZONA COMPREHENSIVE CANCER CONTROL (AZ CCC)
RESEARCH COMMITTEE MEETING MINUTES
September 28, 2006
12:00 pm – 1:00 pm
ADHS Room 565B
Call-in 602-542-9001

In Attendance

Michael Berens, Zeenat Mahal, Jacqueline Palmenberg, Barbara Kavanagh, John Carpten, Tim Flood, Chris Newton, Kendra Sabol

Cancer Network Analysis

No one present to discuss this topic.

Tissue Banking Assessment

Tim's previous reports identified the count of patients seen at various hospitals where pathologic tissue has likely been removed. The committee recommends determining whether these hospitals have a tissue bank and whether the specimens are available to researchers. John recommended addressing these questions by including the high volume hospitals in the Cancer Network Analysis.

A discussion ensued about the kinds of questions to ask in the survey:

Is there a tissue bank at the hospital?"

Does the bank specialize in a particular site (eg, pancreas, prostate, breast)?

How does a researcher make a withdrawal?

Are there IRB requirements; if so, what are they?

Who is using the bank now?

What information is collected when a specimen is banked?

Collecting tissue is important to family history, time of progression, survival to name a few. Studies with high impact are prospective. The University of Arizona Medical Center is trying to identify six sites for pilot projects that have IRB approval with standardized specimen collection procedures. Timing for patient advocacy is important. Patient advocacies would educate patients and encourage questions regarding research with their tissue. Health care agencies can assist with this project. A recommendation was made to utilize investigators whose works would be accelerated by the efforts of this committee. Utility can be shown in linking networks. The question was asked "How do we identify these programs?" Ray Nagel, pathologist at the University of Arizona Medical Center is a key contact and is willing to participate. There still may be barriers to getting tissue information from the University of Arizona Medical Center. The recommendation again was made that Keith incorporate tissue banking as part of Cancer Network Analysis. Scott and Tim are to followup with Keith.

Barbara and Jackie volunteered to work on the issues surrounding patient advocacy. An action item is to set benchmarks or goals for mechanisms to empower patients to accelerate research. The model would be the one that has the most influence and the most prevalent disease. The process would be to accelerate research. A

recommendation was made to connect with Google. To alert Google and work with them to impact research. Issues need to be addressed right up front. Zeenat suggested that the ITCA training course called "Cancer 101" could be updated with a chapter on patient advocacy and the importance of tissue-banking on the next revision. Educational materials and written media were discussed with the purpose of developing a model for patient advocacy. Issues of health disparities need to be taken into consideration. Another goal would be to increase the standard of care by involving tissue specimens. An action item would be for Jackie and Barbara to develop a process for patient advocacy and circulate it to the committee. An action item would be to make linkages between tissue and analysis. An action item would be for John and Mike to select tissues.

Potential Other Projects

NCI will be funding 2-3 demonstration projects. Flinn Foundation held a meeting in which Banner, Scottsdale Health Center, and Tgen attended. Jennifer will contact Sandra Johnson to discuss CCC. No further discussion.

Next Meeting

Thursday, October 26 from 12:00 Noon – 1:00 p.m. Call-in number will be 602-542-9001.